

UK INFANTILE SPASMS TRUST

England & Wales - Charity number 1172167

Details

Other names UKIST - UK INFANTILE SPASMS TRUST

Status Registered

Legal form CIO

Registered 2017-03-21

Register [View on the Charity Commission register](#)

Contact

Address 28 Overhill Road
Bristol
BS16 5DN

Phone 0117 956 8868

Email UKINFANTILESPASMSTRUST@GMAIL.COM

Website <https://ukinfantilespasmstrust.org>

Activities

Objects: THE RELIEF OF THE NEEDS OF THOSE SUFFERING FROM INFANTILE SPASMS OR WEST SYNDROME BY (BUT NOT EXCLUSIVELY):(A) THE PROVISION OF INFORMATION, ADVICE, OTHER ASSISTANCE AND SUPPORT TO CHILDREN, PARENTS, FAMILIES AND CARERS OF THOSE AFFECTED BY INFANTILE SPASMS OR WEST SYNDROME;(B) THE PROMOTION OF RESEARCH INTO THE CAUSES AND TREATMENT OF INFANTILE SPASMS OR WEST SYNDROME AND THE PUBLICATION OF THE USEFUL RESULTS OF SUCH RESEARCH;(C) RAISING THE AWARENESS OF THE PUBLIC AND OF THE MEDICAL PROFESSIONS ON ANY MATTER RELATED TO THE CHARITIES OBJECTS(D) PROVIDING INFORMATION AND TRAINING TO THE MEDICAL PROFESSIONS ON ANY MATTER RELATED TO THE CHARITIES OBJECTS.

Activities: Raising money to help families who have children who suffer from spasms with support and care.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£87,099	£40,354	-	-
2024-04-05	£44,248	£23,833	-	-
2023-04-05	£23,820	£16,025	-	-
2022-04-05	£45,795	£16,830	-	-
2021-04-05	£40,081	£15,949	-	-

Trustees

Name	Role	Appointed
JENNIFER RAWLING	Chair	2017-03-21
Alice Goldhill		2020-05-02
Amy Louise Dowding		2022-03-26
Chloe Amber Louise Cox		2024-02-24
Louisa Coyle		2020-05-02
Louise Elizabeth Derbyshire		2023-03-04
SAMIA SANDERS		2017-03-21

UK INFANTILE SPASMS TRUST

England & Wales - Charity number 1172167

Accounts

Trustees' Annual Report for the period

	Period start date				Period end date		
From	01	04	2024	To	31	03	2025

Section A Reference and administration details

Charity name UK Infantile Spasms Trust

Other names charity is known by UKIST

Registered charity number (if any) 1172167

Charity's principal address 28 Overnhill Road

Bristol

Postcode BS16 5DN

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Jenny Rawling	Chair		
2	Susan Blackburn	Treasurer		
3	Michelle Scoffield			
4	Louisa Coyle			
5	Alice Goldhill			
6	Samia Sanders			
7	Amy Dowding			
8	Louise Derbyshire			
9	Kelly Skinner			
10	Chloe Cox			
11				
12				

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	
N/A	

Names and addresses of advisers (optional information)

Type of Adviser	Name	Address

Name of Chief Executive or names of Senior staff members (optional information)

Name	Dates acted if not for whole year
N/A	

Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Charitable Incorporated Organisation (CIO)
How the charity is constituted (eg. trust, association, company)	Trust / CIO
Trustee selection methods (eg. appointed by, elected by)	Appointed by Trustees at the Annual General Meeting (AGM)

Additional governance issues (Optional information)

<p>You may choose to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> • policies and procedures adopted for the induction and training of trustees; • the charity's organisational structure and any wider network with which the charity works; • relationship with any related parties; • trustees' consideration of major risks and the system and procedures to manage them. 	<p>Charity Commission learning material (The essential trustee: what you need to know, what you need to do) DBS check NSPCC safeguarding course NCVO membership for ongoing Trustee support & guidance</p> <p>A new Trustee induction process is underway</p> <p>The charity is strengthening the wider networks by attending national medical conferences with plans to attend the Infantile Spasms Action Network (ISAN) conference in Washington, USA.</p> <p>Membership of UK RET, CREA and ISAN</p> <p>Trustees are reimbursed for travel expenses for attending charity events and the AGM. The expense policy is derived from the Charity Commission guidance.</p> <p>A conflict-of-interest policy is in place; a conflict register is in place and conflict of interest is an agenda point at the monthly Board meetings</p> <p>A risk policy is in place; the risk register is updated as required by the Chair and Treasurer with a full annual review by the Board</p>
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Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

The purpose of the charity is to provide relief of the needs of those suffering from Infantile Spasms or West Syndrome, as well as promote awareness and support clinical research into infantile spasms.

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

As follows but not exclusively:

- a) The provision of information, advice and other assistance and support to children, parents, families and carers of those affected by Infantile Spasms
- b) The promotion of research into the causes and treatment of Infantile Spasms and the publication of useful results of this research. Granting £10,000 funding to the BEE Project at Kings College hospital with further commitment to supporting infantile Spasms projects in 2025.
- c) Raising the awareness of the public and of the medical professions on any matter relating to the charity objectives. The medical education training course is in the final stages of completion and will be launched in 2025-26.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grant making;
- policy programme related investment;
- contribution made by volunteers.

UKIST has a documented grant award policy which is reviewed annually. The grant criteria and application form are on the website and are reviewed annually alongside the policy.

UKIST has a system for managing processes and policies and this is reviewed annually by the Board

Trustees and the Facebook admin team are volunteers. Their contribution, knowledge and skills ensure that the charity is managed effectively, and that it is sustainable.

Over the next 12 months UKIST will be working with The Cranfield Trust to develop their strategy and business plan, which will lead to charity growth and long-term plans to appoint staff.

Summary of the main achievements of the charity during the year

Review UKIST's annual newsletter, follow the link below

[newsletter_2025.pdf](#)

Section E

Financial review

Brief statement of the charity's policy on reserves

The charity has a reserves policy and has made great strides in actioning the necessary steps to ensure reserves are managed well, not only in terms of including 3 months operational costs but it also has designated funds for future expenditure commitments.

Details of any funds materially in deficit

Not applicable

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

The charity's principal source of funding is by families affected by infantile spasms (IS), family friends and charity Trustees. £20,000 was generously donated by The Phillips 2012 Charitable Trust. In April 2025 UKIST will participate in the London Landmark Half Marathon (LLHM) and will be looking to expand on including participatory events in future.

A new fundraising initiative is in progress, UKIST has applied to The Spectris Foundation for a £5,000 grant to deliver a health and wellbeing project for parents of IS babies/children. A Spectris employee, also a member of the UKIST Facebook group, nominated UKIST for the grant award.

Expenditure is managed via a budget to ensure that costs are controlled, and it is a point on the monthly Board meetings agenda. The annual budget is set at the Annual General Meeting (AGM) and budget variations are reviewed regularly to ensure funding is available to achieve the charity's key objectives.

The Xero finance system has recently been introduced to provide accounting management and relevant income and expenditure reporting. This affords all Trustees full oversight as well as providing read-only access to the current bank account transactions.

A high interest, 60-day term new account will protect funds above £85,000, as per FSCS guidance. The bank of choice reinvests all its profits into the charity sector. Drafting an investment policy is in future plans.

Section F

Other optional information

Section G**Declaration**

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees:

Signature/s		
Full Name/s		
Position (e.g. Secretary, Chair etc)		
Date		

Unaudited accounts

UK Infantile Spasms Trust

Year ended 31 March 2025

Prepared: 20th May 2025
Finalised: 15th July 2025
By Norton Accountancy Ltd

ACCOUNTS FOR UKIST
FOR THE PERIOD ENDED 31 MARCH 2025
ACCOUNTANTS CERTIFICATE

We have prepared the attached accounts, without audit from the records and information supplied to us, and we confirm that they are in accordance therewith.



Jane Norton FMAAT
Norton Accountancy

Licence no. 0521

31 / 07 / 2025

Date

CLIENT'S SIGNATURE

I have read the accounts prepared by Norton Accountancy and approve the figures

S Blackburn



Signed

03 / 08 / 2025

Date

J Rawling



Signed

07 / 08 / 2025

Date

UKIST
Profit & loss statement
Year ended 31 March 2025

	<u>2025</u>		<u>2024</u>	
	<u>£</u>	<u>£</u>	<u>£</u>	<u>£</u>
<i>Income</i>				
Donations received		67,099		44,248
Grants		<u>20,000</u>		<u>-</u>
		87,099		44,248
<i>Expenditure</i>				
Accountancy	522		600	
Bank charges	202		40	
Computer	4		-	
Grants	11,365		11,583	
One-off research donation	10,000		-	
Medical platform	9,492		-	
Family support	299		1,784	
Insurance	365		441	
Training and research	307		793	
Subs	562		446	
Promotional items	713		1,585	
Printing, postage & stationary	281		293	
Admin	2,846		1,889	
Sponsorship	2,952		4,152	
Sundry	353		136	
Social media & website	<u>92</u>		<u>92</u>	
		40,354		23,833
Profit for the year		<u>46,744</u>		<u>20,415</u>

UKIST
Balance sheet
Year ended 31 March 2025

	<u>2025</u>		<u>2024</u>
<i><u>Current assets</u></i>			
Bank balance	152,823		124,909
Accrued income	20,192		-
Prepayments	<u>3,072</u>		<u>-</u>
	176,087		124,909
<i><u>Current liabilities</u></i>			
Accruals	-4,734		-300
Total assets less liabilities	<u>171,353</u>		<u>124,609</u>
Retained profits b/fwd	124,609		104,194
Profit in year	46,744		20,415
Retained profits c/fwd	<u>171,353</u>		<u>124,609</u>

Notes to the accounts

1 - Restricted reserves

Going forward the trustees will be recognising restricted reserves to cover certain projects or investments. As at 31.3.2025, these were identified as totalling £62,343 for the investments in a medical education platform, on-going research costs and grants to families.

In addition, overheads for the next 12 months have also been restricted from spending so there is a contingency buffer in place to cover any drop in income. This totalled £9,541 and covers items such as AGM costs, conference costs, software, admin and various other smaller annual costs.

On that basis, the total restricted reserves at 31.3.2025 were £71,884. Going forward, the following note will be included:

	<u>Restricted</u> <u>for research</u> <u>& projects</u>	<u>Restricted</u> <u>overhead</u> <u>fund</u>	<u>Unrestricted</u> <u>Income</u> <u>Funds</u>	<u>£</u>
At 01.04.2024	-	-	124,609	124,609
Net incoming resources	-	-	46,744	46,744
Reallocation of reserves per note	<u>62,343</u>	<u>9,541</u>	<u>-</u>	<u>-</u>
At 31.03.2025	<u>62,343</u>	<u>9,541</u>	<u>99,469</u>	<u>171,353</u>



Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity Name
UK Infantile Spasms Trust

On accounts for the year
ended

5th April 2025

Charity no
(if any)

1172167

Set out on pages

1+2

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 05/04/2020.

Responsibilities and
basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:

Date:

3.7.25

Name:

SARAH JENKINS

Relevant professional
qualification(s) or body

FMAAT

Address:

Norton Accountancy Ltd

7 Soundwell Road

Bristol BS16 4QG

Section B**Disclosure**

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

None – the charity appears to be well run with no concerns.

UK INFANTILE SPASMS TRUST

England & Wales - Charity number 1172167

Accounts



Trustees' Annual Report for the period

From 6 April 2023 to 5 April 2024

Charity name: UK Infantile Spasms Trust

Charity registration number: 1172167

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	The purpose of the charity is to provide a relief of the needs of those suffering from Infantile Spasms or West Syndrome, as well as promote awareness and support clinical research into infantile spasms.
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	As follows but not exclusively: a) The provision of information, advice and other assistance and support to children, parents, families and carers of those affected by Infantile Spasms b) The promotion of research into the causes and treatment of Infantile Spasms and the publication of useful results of this research c) Raising the awareness of the public and of the medical professions on any matter relating to the charity objectives
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	n/a

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	Policy drafted / effective May 2024.
	Para 1.38	n/a

Policy on social investment including program related investment		
Other		

Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	<p>The charity provides support to around 1300 families with children affected by Infantile Spasms. This includes sharing information, education, support and grants.</p> <p>It also improves the awareness of the symptoms of Infantile Spasms across the general public as well as within medical professions.</p> <p>The charity also supports the advancement of clinical research into the condition to help children suffering now and in the future.</p>

Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	Achieving
Performance of fundraising activities against objectives set	Para 1.41	Achieving
Investment performance against objectives	Para 1.41	Profit is made annually therefore achieved
Other		

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	Financial position remains strong. Cash in bank allocated to future year budget, with sufficient funds to cover run costs.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	A significant percentage of the reserves currently held in the bank account have been ring-fenced for the imminent investment in a UKIST-owned primary healthcare education package which will roll out UK wide throughout 2024 and beyond (final payment for project is pending completion of work, expected H2 2024).
Amount of reserves held	Para 1.22	£ 104,494.00
Reasons for holding zero reserves	Para 1.22	n/a
Details of fund materially in deficit	Para 1.24	n/a
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	None

Additional information (optional)

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	The charity's principal source of funds is from donations and fundraising events.
Investment policy and objectives including any social investment policy adopted.	Para 1.46	None
A description of the principal risks facing the charity	Para 1.46	Insufficient donations are made to keep the charity afloat. This doesn't seem to have been an issue in the accounting year and even through COVID previously.
Other		

Structure, Governance and Management

Description of charity's trusts:		
Type of governing document	Para 1.25	Charitable Incorporated Organisation (CIO)
How is the charity constituted?	Para 1.25	Trust/CIO
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	Appointed by trustees normally at AGM

Additional information (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	<ul style="list-style-type: none"> • Charity Commission learning material (The essential trustee: what you need to know, what you need to do) • DBS check • NSPCC safeguarding course • NVCO membership for ongoing Trustee support & guidance
The charity's organisational structure and any wider network with which the charity works	Para 1.51	n/a
Relationship with any related parties	Para 1.51	n/a
Other		n/a

Reference and Administrative details

Charity name	UK Infantile Spasms Trust
Other name the charity uses	n/a
Registered charity number	1172167
Charity's principal address	28 Overnhill Road Downend Bristol BS16 5DN

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Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Michelle Scoffield	Treasurer		
2	Jennifer Rawling	Chair		
3	Louisa Coyle			
4	Alice Goldhill			
5	Samia Sanders			
6	Amy Dowding			
7	Louise Derbyshire		Appointed 26 March 23	
8	Susan Blackburn		Appointed 24 February 24	UKIST AGM - Trustees
9	Kelly Skinner		Appointed 24 February 24	UKIST AGM - Trustees
10	Chloe Cox		Appointed 24 February 24	UKIST AGM - Trustees
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	None
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	None
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	None

Additional information (optional)

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address
Accountants	Norton Accountancy Ltd	7 Soundwell Road, Staple Hill, Bristol BS16 4QG

Name of chief executive or names of senior staff members (Optional information)

Not applicable

Exemptions from disclosure

Reason for non-disclosure of key personnel details

Not applicable

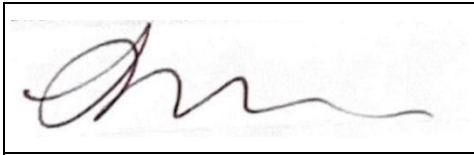
Other optional information

Further information on 2023-2024 progress can be found here - [UKIST-update-2024.pdf \(ukinfantilepasmstrust.org\)](#)

Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Sarah Jenkins	
Position (eg Secretary, Chair, etc)	Advisor	
Date	16.1.25	

Unaudited profit and loss report

for

UK Infantile Spasms Trust

Year ended 5 April 2024

Prepared: 21st May 2024
Finalised: 12th June 2024
By Norton Accountancy Ltd

ACCOUNTS FOR UKIST

FOR THE PERIOD ENDED 5 APRIL 2024

ACCOUNTANTS CERTIFICATE

We have prepared the attached accounts, without audit from the records and information supplied to us, and we confirm that they are in accordance therewith.

Jane Norton FMAAT
Norton Accountancy

Date

Licence no. 0521

CLIENT'S SIGNATURE

I have read the accounts prepared by Norton Accountancy and approve the figures

S Blackburn

Signed

Date

M Scoffield

Signed

Date

UKIST
Profit & loss statement
Year ended 5 April 2024

	2024		2023	
	£	£	£	£
<i>Income</i>				
Donations received		44,248		23,820
Grants		-		-
		<u>44,248</u>		<u>23,820</u>
<i>Expenditure</i>				
Accountancy	600		-	
Bank charges	40		-	
Grants	11,583		8,165	
Family support	1,784		1,213	
Insurance	441		439	
Training and research	793		270	
Subs	446		216	
Promotional items	1,585		725	
Printing, postage & stationary	293		103	
Admin	1,889		2,827	
Sponsorship	4,152		1,597	
Sundry	136		269	
Social media & website	92		200	
		<u>23,833</u>	<u>16,024</u>	
Profit for the year		<u>20,415</u>	<u>7,796</u>	



Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity Name
UK Infantile Spasms Trust

On accounts for the year
ended

5th April 2024

Charity no
(if any)

1172167

Set out on pages

1+2

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 05/04/2020.

Responsibilities and
basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:

Date:

16.1.25

Name:

SARAH JENKINS

Relevant professional
qualification(s) or body

FMAAT

Address:

Norton Accountancy Ltd

7 Soundwell Road

Bristol BS16 4QG

Section B**Disclosure**

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

None – the charity appears to be well run with no concerns.

UK INFANTILE SPASMS TRUST

England & Wales - Charity number 1172167

Accounts



Trustees' Annual Report for the period

From 6 April 2022 to 5 April 2023

Charity name: UK Infantile Spasms Trust

Charity registration number: 1172167

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	The purpose of the charity is to provide a relief of the needs of those suffering from Infantile Spasms or West Syndrome, as well as promote awareness and support clinical research into infantile spasms.
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	As follows but not exclusively: a) The provision of information, advice and other assistance and support to children, parents, families and carers of those affected by Infantile Spasms b) The promotion of research into the causes and treatment of Infantile Spasms and the publication of useful results of this research c) Raising the awareness of the public and of the medical professions on any matter relating to the charity objectives
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	n/a

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	n/a
Policy on social investment including program related	Para 1.38	n/a

investment		
Other		

Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	<p>The charity provides support to around 1300 families with children affected by Infantile Spasms. This includes sharing information, education, support and grants.</p> <p>It also improves the awareness of the symptoms of Infantile Spasms across the general public as well as within medical professions.</p> <p>The charity also supports the advancement of clinical research into the condition to help children suffering now and in the future.</p>

Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	Achieving
Performance of fundraising activities against objectives set	Para 1.41	Achieving
Investment performance against objectives	Para 1.41	Profit is made annually therefore achieved
Other		

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	The charity was once again profit making, however donations received decreased due to less events and a general decline. The profit was £7,795 in 22/23
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	A significant percentage of the reserves currently held in the bank account have been ring-fenced for the imminent investment in a UKIST-owned primary healthcare education package which will roll out UK wide throughout 2024 and beyond (final payment expected to be made in Q4 2023).
Amount of reserves held	Para 1.22	£104,194
Reasons for holding zero reserves	Para 1.22	n/a
Details of fund materially in deficit	Para 1.24	n/a
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	None

Additional information (optional)

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	The charity's principal source of funds is from donations and fundraising events.
Investment policy and objectives including any social investment policy adopted	Para 1.46	None
A description of the principal risks facing the charity	Para 1.46	That not enough donations are made to keep the charity afloat. This doesn't seem to have been an issue in the accounting year and even through COVID previously.
Other		

Structure, Governance and Management

Description of charity's trusts:		
Type of governing document	Para 1.25	Charitable Incorporated Organisation (CIO)
How is the charity constituted?	Para 1.25	Trust/CIO
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	Appointed by trustees normally at AGM

Additional information (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	n/a
The charity's organisational structure and any wider network with which the charity works	Para 1.51	n/a
Relationship with any related parties	Para 1.51	n/a
Other		n/a

Reference and Administrative details

Charity name	UK Infantile Spasms Trust
Other name the charity uses	n/a
Registered charity number	1172167
Charity's principal address	28 Overhill Road Downend Bristol BS16 5DN

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Michelle Schofield			
2	Jenny Rawling			
3	Belen Robbins		Resigned 8 June 22	
4	Louisa Coyle			
5	Alice Goldhill			
6	Samia Sanders			
7	Amy Dowding			
8	Louise Derbyshire		Appointed 26 March 23	
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Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	

Additional information (optional)

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address
Accountants	Norton Accountancy Ltd	7 Soundwell Road, Staple Hill, Bristol BS16 4QG

Name of chief executive or names of senior staff members (Optional information)

Not applicable

Exemptions from disclosure

Reason for non-disclosure of key personnel details

Not applicable

Other optional information

--

Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)

	
---	--

Full name(s)

Sarah Jenkins

Position (eg Secretary,
Chair, etc)

Advisor

Date

13 October 2023

Unaudited profit and loss report

for

UK Infantile Spasms Trust

Year ended 5 April 2023

Prepared: 7th June 2023
Finalised: 21st June 2023
By Norton Accountancy Ltd

ACCOUNTS FOR UKIST

FOR THE PERIOD ENDED 5 APRIL 2023

ACCOUNTANTS CERTIFICATE

We have prepared the attached accounts, without audit from the records and information supplied to us, and we confirm that they are in accordance therewith.

Jane Norton FMAAT
Norton Accountancy

Date

Licence no. 0521

CLIENT'S SIGNATURE

I have read the accounts prepared by Norton Accountancy and approve the figures

J Rawling

Signed

Date

M Scoffield

Signed

Date

UKIST
Profit & loss statement
Year ended 5 April 2023

	2023		2022	
	£	£	£	£
<i>Income</i>				
Donations received		23,820		45,795
Grants				
		<u>23,820</u>		<u>45,795</u>
<i>Expenditure</i>				
Accountancy	300		300	
Grants	8,165		10,673	
Family support	1,213		2,217	
Insurance	439		439	
training and research	270		37	
Subs	216		90	
Promotional items	725		584	
Printing, postage & stationary	103		672	
Admin	2,827		939	
Sponsorship	1,597		762	
Sundry	269		24	
Social media & Website	200		92	
		<u>16,025</u>		<u>16,830</u>
Profit for the year		<u>7,795</u>		<u>28,965</u>

UK INFANTILE SPASMS TRUST

England & Wales - Charity number 1172167

Accounts



Trustees' Annual Report for the period

From 6 April 2021 to 5 April 2022

Charity name: UK Infantile Spasms Trust

Charity registration number: 1172167

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	The purpose of the charity is to provide a relief of the needs of those suffering from Infantile Spasms or West Syndrome
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	As follows but not exclusively: a) The provision of information, advice and other assistance and support to children, parents, families and carers of those affected by Infantile Spasms b) The promotion of research into the causes and treatment of Infantile Spasms and the publication of useful results of this research c) Raising the awareness of the public and of the medical professions on any matter relating to the charity objectives
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	n/a

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	n/a
Policy on social investment including program related investment	Para 1.38	n/a

Other		
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Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	<p>The charity provides support to around 1300 families with children affected by Infantile Spasms. This includes sharing information, education, support and grants.</p> <p>It also improves the awareness of the symptoms of Infantile Spasms across the general public as well as within medical professions.</p> <p>The charity also supports the advancement of clinical research into the condition to help children suffering now and in the future.</p>

Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	Achieving
Performance of fundraising activities against objectives set	Para 1.41	Achieving
Investment performance against objectives	Para 1.41	Profit is made annually therefore achieved
Other		

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	The charity has performed well since COVID and donations received increased leaving a profit of £28965 in 21/22
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	The reserves are held in the charity to cover future costs should there be a period where donations and fundraising efforts do not cover this. Talks are to take place about distributing this to protect the funds and using some of the money to build some UKIST own education materials
Amount of reserves held	Para 1.22	£95,473
Reasons for holding zero reserves	Para 1.22	n/a
Details of fund materially in deficit	Para 1.24	n/a
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	None

Additional information (optional)

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	The charity's principal source of funds is from donations and fundraising events.
Investment policy and objectives including any social investment policy adopted	Para 1.46	None
A description of the principal risks facing the charity	Para 1.46	That not enough donations are made to keep the charity afloat..This doesn't seem to have been an issue in the accounting year and even through COVID previously
Other		

Structure, Governance and Management

Description of charity's trusts:		
Type of governing document	Para 1.25	Charitable Incorporated Organisation (CIO)
How is the charity constituted?	Para 1.25	Trust/CIO
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	Appointed by trustees normally at AGM

Additional information (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	n/a
The charity's organisational structure and any wider network with which the charity works	Para 1.51	n/a
Relationship with any related parties	Para 1.51	n/a
Other		n/a

Reference and Administrative details

Charity name	UK Infantile Spasms Trust
Other name the charity uses	n/a
Registered charity number	1172167
Charity's principal address	28 Overhill Road Downend Bristol BS16 5DN

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Michelle Schofield			
2	Jenny Rawling			
3	Belen Robbins			
4	Louisa Coyle			
5	Alice Goldhill			
6	Samia Sanders			
7	Amy Dowding		26 March 2022	Appointed at AGM
8				
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20				

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	

Additional information (optional)

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address
Accountants	Norton Accountancy Ltd	7 Soundwell Road, Staple Hill, Bristol BS16 4QG

Name of chief executive or names of senior staff members (Optional information)

Not applicable

Exemptions from disclosure

Reason for non-disclosure of key personnel details

Not applicable

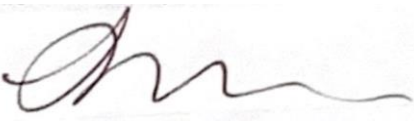
Other optional information

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Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Sarah Jenkins	
Position (eg Secretary, Chair, etc)	Advisor	
Date	2 November 2022	

Unaudited profit and loss report

for

UK Infantile Spasms Trust

Year ended 5 April 2022

Prepared: 31st May 2022
Finalised: 8th June 2022
By Norton Accountancy Ltd

ACCOUNTS FOR UKIST

FOR THE PERIOD ENDED 5 APRIL 2022

ACCOUNTANTS CERTIFICATE

We have prepared the attached accounts, without audit from the records and information supplied to us, and we confirm that they are in accordance therewith.

Jane Norton FMAAT
Norton Accountancy

Date

Licence no. 0521

CLIENT'S SIGNATURE

I have read the accounts prepared by Norton Accountancy and approve the figures

J Rawlings

Signed

Date

M Scoffield

Signed

Date

UKIST
Profit & loss statement
Year ended 5 April 2022

	<u>2022</u>		<u>2021</u>	
	<u>£</u>	<u>£</u>	<u>£</u>	<u>£</u>
<i>Income</i>				
Donations received		45,795		32,998
Grants		-		7,083
		<u>45,795</u>		<u>40,081</u>
<i>Expenditure</i>				
Accountancy	300		300	
Grants	10,673		2,816	
Family support	2,217		5,121	
Insurance	439		431	
training and research	37		6,349	
Subs	90		150	
Promotional items	584		361	
Printing, postage & stationary	672		237	
Admin	939		-	
Sponsorship	762		-	
Sundry	24		-	
Social media & Website	92		176	
		<u>16,830</u>		<u>15,949</u>
Profit for the year		<u>28,965</u>		<u>17,049</u>



Section A

Independent Examiner's Report

Report to the trustees/ members of

Charity Name
UK Infantile Spasms Trust

On accounts for the year ended

5th April 2022

Charity no (if any)

1172167

Set out on pages

1+2

Responsibilities and basis of report

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 05/04/2020.

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:

Date:

Name:

Relevant professional qualification(s) or body (if any):

FMAAT

Address:

Norton Accountancy Ltd
7 Soundwell Road
Bristol BS16 4QG

Section B

Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

None - the charity appears to be well run with no concerns.

UK INFANTILE SPASMS TRUST

England & Wales - Charity number 1172167

Accounts

Unaudited profit and loss report

for

UK Infantile Spasms Trust

Year ended 5 April 2021

Prepared 30 April 2021
Finalised 11 May 2021
By Norton Accountancy Ltd

ACCOUNTS FOR UKIST

FOR THE PERIOD ENDED 5 APRIL 2021

ACCOUNTANTS CERTIFICATE

We have prepared the attached accounts, without audit from the records and information supplied to us, and we confirm that they are in accordance therewith.



Jane Norton FMAAT
Norton Accountancy

23 / 08 / 2021 Date

Licence no. 0521

CLIENT'S SIGNATURE

I have read the accounts prepared by Norton Accountancy and approve the figures

J Rawlings



Signed

24 / 08 / 2021

Date

M Scoffield



Signed

23 / 08 / 2021

Date

UKIST
Profit & loss statement
Year ended 5 April 2021

	<u>£</u>
<i><u>Income</u></i>	
Donations received	32,998
Grants	<u>7,083</u>
	40,081
<i><u>Expenditure</u></i>	
Accountancy	300
Grants	2,816
Family support	5,121
Insurance	431
training and research	6,349
Subs	158
Promotional items	361
Printing, postage & stationary	237
Social media & Website	<u>176</u>
	15,949
Profit for the year	<u><u>17,049</u></u>



Trustees' Annual Report for the period

From 6 April 2020 to 5 April 2021

Charity name: UK Infantile Spasms Trust

Charity registration number: 1172167

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	The purpose of the charity is to provide a relief of the needs of those suffering from Infantile Spasms or West Syndrome
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	As follows but not exclusively: a) The provision of information, advice and other assistance and support to children, parents, families and carers of those affected by Infantile Spasms b) The promotion of research into the causes and treatment of Infantile Spasms and the publication of useful results of this research c) Raising the awareness of the public and of the medical professions on any matter relating to the charity objectives
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	n/a

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	n/a
Policy on social investment including program related investment	Para 1.38	n/a

Other		
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Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	<p>The charity provides support to around 1300 families with children affected by Infantile Spasms. This includes sharing information, education, support and grants.</p> <p>It also improves the awareness of the symptoms of Infantile Spasms across the general public as well as within medical professions.</p> <p>The charity also supports the advancement of clinical research into the condition to help children suffering now and in the future.</p>

Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	Achieving
Performance of fundraising activities against objectives set	Para 1.41	Achieving
Investment performance against objectives	Para 1.41	Profit is made annually therefore achieved
Other		

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	The charity has performed well in the face of COVID and donations were still received leaving a profit of £17,049 in 2020/21.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	The reserves are held in the charity to cover future costs should there be a period where donations and fundraising efforts do not cover this.
Amount of reserves held	Para 1.22	£66,269
Reasons for holding zero reserves	Para 1.22	n/a
Details of fund materially in deficit	Para 1.24	n/a
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	None

Additional information (optional)

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	The charity's principal source of funds is from donations and fundraising events.
Investment policy and objectives including any social investment policy adopted	Para 1.46	None
A description of the principal risks facing the charity	Para 1.46	That not enough donations are made to keep the charity afloat. COVID has taken place during this year but the charity has still made a profit and we don't expect the current year to be affected.
Other		

Structure, Governance and Management

Description of charity's trusts:		
Type of governing document	Para 1.25	Charitable Incorporated Organisation (CIO)
How is the charity constituted?	Para 1.25	Trust/CIO
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	Appointed by trustees normally at AGM

Additional information (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	n/a
The charity's organisational structure and any wider network with which the charity works	Para 1.51	n/a
Relationship with any related parties	Para 1.51	n/a
Other		n/a

Reference and Administrative details

Charity name	UK Infantile Spasms Trust
Other name the charity uses	n/a
Registered charity number	1172167
Charity's principal address	28 Overnhill Road Downend Bristol BS16 5DN

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Michelle Schofield			
2	Jenny Rawling			
3	Belen Robbins			
4	Louisa Coyle		From 2 May 2020	Appointed at AGM
5	Alice Goldhill		From 2 May 2020	Appointed at AGM
6	Samia Sanders			
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Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	

Additional information (optional)

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address
Accountants	Norton Accountancy Ltd	7 Soundwell Road, Staple Hill, Bristol BS16 4QG

Name of chief executive or names of senior staff members (Optional information)

Not applicable

Exemptions from disclosure

Reason for non-disclosure of key personnel details

Not applicable

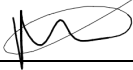

Other optional information

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Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Michelle Schofield	Jenny Rawling
Position (eg Secretary, Chair, etc)	Treasurer	Trustee
Date	5 August 2021	

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DOCUMENT ID	2dfc8222072fda0abea57bdb381e8680bbf71c43
AUDIT TRAIL DATE FORMAT	DD / MM / YYYY
STATUS	● Completed

Document history



SENT

23 / 08 / 2021

08:19:32 UTC

Sent for signature to Sarah Jenkins (sarah@nortonaccountancy.co.uk), Michelle Scoffield (michellescoffield@hotmail.com) and Jenny Rawling (jenny.rawling@googlemail.com) from docs@nortonaccountancy.co.uk
IP: 109.73.121.1



VIEWED

23 / 08 / 2021

08:21:31 UTC

Viewed by Sarah Jenkins (sarah@nortonaccountancy.co.uk)
IP: 109.73.121.1



SIGNED

23 / 08 / 2021

08:22:17 UTC

Signed by Sarah Jenkins (sarah@nortonaccountancy.co.uk)
IP: 109.73.121.1



VIEWED

23 / 08 / 2021

10:40:26 UTC

Viewed by Michelle Scoffield (michellescoffield@hotmail.com)
IP: 176.250.51.9



SIGNED

23 / 08 / 2021

10:40:47 UTC

Signed by Michelle Scoffield (michellescoffield@hotmail.com)
IP: 176.250.51.9

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STATUS	● Completed

Document history

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